

Ginny Miller  
Wednesday, March 12, 2008  
Joint Committee on Public Health

**SB 654 An Act Concerning the Availability of Prescribed Antiepileptic Drugs**

My name is Ginny Miller and I am from Dayville , Ct.

Thank you for allowing me time to speak to you about something that is very important to me, my family and the 60,000 people with epilepsy in our state.

This bill is important to people with epilepsy because they rely so much on their medications to prevent them from having seizures. It will allow people with epilepsy to regain control; control of their seizures as well as their seizure medications. Epilepsy already takes away control of so much in our lives. Please give us back control of our generic medications when we need to use them.

My son Samuel has been dealing with seizures for over half of his life. He will turn 17 in March, is a junior in high school, and has maintained honors or high honors for all but one term of his entire high school career. He is involved in a drama team, plays in the band for our Youth ministry, and is the worship leader for our Children's program at church. Last October he started a T-shirt business and outreach for teens and young adults dealing with depression called Preventing Teen Tragedy.

On June 5, 2006 the pharmacist handed my husband the 4<sup>th</sup> variation of the generic Zonisamide in 6 months. The previous week Sam had 5 breakthrough seizures after 7 weeks of seizure control. This was the longest time of control he had seen up till then. We already had to change the Zonisamide dose because of a severe reaction and rapid weight loss causing him to loose 14 pounds in less than 2 months. We were waiting for testing to rule out Type 1 diabetes which my father had. I had warned my husband to check the pill color before returning home to make sure it was our usual Mylon Zonisamide, the type we needed. I knew to check this because a friend had been taught by her pharmacist how important this was and that breakthrough seizures could occur. This pharmacist ensured that her own son only had two manufacturers to go between. I then looked up the Hatch/Waxman Act on generics and understood the differences between the manufacturers and how important it was that Sam get the consistency. I went back to the pharmacy leaving my husband at home to answer the phone since both the Pediatrician and Epileptologist were due to call. I asked that they take back Zonisamide # 4 and call around to find # 3 in one of their many stores since we were weaning and only needed a one month supply. I explained that Sam COULD NOT handle another medication change during this chaotic time because it would be like changing a third medication. This is unacceptable in the delicate balance of epilepsy management.

Prior to allowing the generic I had asked the epileptologist if the generic would be all right when the insurance said we had to switch to this in January. I had not known enough to tell him about

the manufacturer changes. If we had been notified before a change we would have turned it down and sought another pharmacy to keep the consistency that Sam needed. If the epileptologist had been notified he could have ordered blood work and adjusted the medication to maintain consistent levels. If we have the option to be notified, as with this legislation, we have a choice to be more careful. And as with any medication change, the doctor can order blood work to assess whether there needs to be further adjustments to the medications. Sam's doctor is in Boston; he is not close by and having the pharmacist notify him and work with us is so very important...

My son has still not regained control. We had a hospital stay within weeks of this loss of control! Thankfully his weight loss was a side effect and not diabetes. His seizures still resist control and we have changed medications several times still. This whole experience has taught us that it is vital that we be informed of manufacturer changes when dealing with these narrow therapeutic index medications.

Please support this legislation and prevent others from having to go through what we did – or something even worse -- just because the pharmacists who are supposed to be members of our health care team, choose to ignore the fact that this is a huge problem for everyone who has epilepsy.

Thank you for your attention!